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An integrative review: understanding driving retirement decisions for individuals living with a dementia

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Abstract

Aim To synthesise primary research exploring decision making practices used to determine the time to retire from driving for individuals living with a dementia. **Background** Driving requires complex cognitive and physical skills potentially compromised due to the progressive nature of dementia. Whilst on-road assessments are considered reliable indicators of driving capacity by clinicians, drivers with dementia disagree. **Design** Integrative literature review informed by Whittemore & Knafl (2005). **Data sources** Electronic database search of Medline, CINAHL, Web of Science, Google Scholar 1997-2012; and incremental hand search. **Review methods** Primary studies published in peer reviewed journals were appraised against quality assessment criteria using CASP methodological assessment tools. **Results** A total of 43 studies were retained for synthesis. Key findings were abstracted and a themes matrix was generated to identify patterns of meaning. Six themes emerged: (i) dementia may compromise the complex task of driving; (ii) defining onset and severity of dementia is problematic; (iii) symptom progression impacts on driving skills; (iv) assessment of fitness to drive remains subjective; (v) some drivers are reluctant to accept negative assessment outcomes; and (vi) the search for effective strategies to enhance acceptance of driver retirement continues. **Conclusion** This integrative literature review identified a large body of knowledge exploring the issues of driving cessation for drivers with dementia. However a challenge remains for practitioners, drivers and their family carers regarding how best to address this highly emotive issue. Findings could inform a structured approach to address this sensitive topic in a timely manner.

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REVIEW PAPER

An integrative review: understanding driving retirement decisions for individuals living with a dementia*

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Abstract

Aim. To synthesise primary research exploring decision making practices used to determine the time to retire from driving for individuals living with a dementia.

Background. Driving requires complex cognitive and physical skills potentially compromised due to the progressive nature of dementia. Whilst on-road assessments are considered reliable indicators of driving capacity by clinicians, drivers with dementia disagree.

Design. Integrative literature review informed by Whittemore & Knafl (2005).

Data sources. Electronic database search of Medline, CINAHL, Web of Science, Google Scholar 1997–2012; and incremental hand search.

Review methods. Primary studies published in peer reviewed journals were appraised against quality assessment criteria using CASP methodological assessment tools.

Results. A total of 43 studies were retained for synthesis. Key findings were abstracted and a themes matrix was generated to identify patterns of meaning. Six themes emerged: (i) dementia may compromise the complex task of driving; (ii) defining onset and severity of dementia is problematic; (iii) symptom progression impacts on driving skills; (iv) assessment of fitness to drive remains subjective; (v) some drivers are reluctant to accept negative assessment outcomes; and (vi) the search for effective strategies to enhance acceptance of driver retirement continues.

Conclusion. This integrative literature review identified a large body of knowledge exploring the issues of driving cessation for drivers with dementia. However a challenge remains for practitioners, drivers and their family carers regarding how best to address this highly emotive issue. Findings could inform a structured approach to address this sensitive topic in a timely manner.

Keywords: assessment, care pathways, decision-making, dementia, ethics, nurses, nursing, patient participation

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Why is this research or review needed?

- As the population ages and dementia prevalence rates increase, the number of drivers living with dementia will increase.
- On-road assessments are considered the most reliable evidence for driving capacity, however when faced with the results from these tests, drivers with dementia often reject their validity.
- Research was required to understand alternative approaches that could be implemented in clinical practice to enable individuals living with a dementia to make a decision to retire from driving.

What are the key findings?

- Healthcare practitioners should initiate conversations about driving with individuals living with a dementia and their family carers as soon as cognitive and memory problems are noticed.
- Driving means more to individuals than a practical transport choice, so discussions about driving retirement with individuals living with a dementia need to reflect the complexity of this decision.

How should the findings be used to influence policy/practice/research/education?

- Policy needs to acknowledge that a diagnosis of dementia happens many years after initial signs of cognitive and memory problems occur; and the responsibilities of practitioners for assessing driving capacity need to be related to specific impairments rather than a disease.
- Practice needs to include strategies for healthcare practitioners to raise awareness among individuals living with a dementia about the importance of planning for driving retirement.
- Research needs to explain how practitioners can positively support individuals living with a dementia to make decisions about driving retirement.

Introduction

Empirical evidence confirms that dementia is a chronic condition progressively influencing cognitive function and potentially, the capacity to drive safely (Duchek *et al.* 2003, Carr *et al.* 2005). However, factors that enable or inhibit acceptance of driving retirement for individuals living with a dementia are not clear (Andrew 2012). This article discusses findings from an integrative literature review regarding the highly emotive issue of driver retirement and proposes that the most effective means of enabling acceptance of driving cessation for those individuals living with a dementia has not yet been determined.

Background

Driving is an important activity of daily living demonstrated by the fact that most Australians aged between 30-70 have a driver's licence (Austroads National Road Transport Commission 2012). The debate about driving age and driver safety for road users, policymakers and the wider community is expected to intensify with the predicted increase in the average age of the Australian population over the next 50 years (Australian Bureau of Statistics 2008). The complexity of driving has important implications for this driving-oriented society, given the estimate that 200,000 Australians, currently driving, have dementia and this number is projected to reach 730,000 by 2050 (Deloitte Access Economics 2011). Key issues of social concern should not be limited to the age of licence holders. It is important that individual drivers are able to demonstrate the physical and cognitive competencies essential for safe driving, regardless of age.

Driving is a high-level skill requiring selective attention to relevant cues, quick response to changing environments and the ability to predict hazards (Adler *et al.* 2006). Safe driving relies on the ability to perform habitual motor functions, for example, operating the gears, brake and accelerator (long-term memory) while simultaneously responding to changing environments of variable complexity (new learning). For those with dementia, these abilities may be compromised due to an associated decline in motor responsiveness and cognitive processing speed (Fox *et al.* 1997, Duchek *et al.* 2003, Brown *et al.* 2005a,b, Perkinson *et al.* 2005). Consequently, drivers with dementia who continue to drive may be at higher risk of road accidents when compared with their peers (Whelihan *et al.* 2005). A review of motor vehicle crash risk, found that drivers with dementia were 2-2.5 times more likely to be involved in an accident compared with age and sex-matched controls (Hogan *et al.* 2008).

Dementia's progressive nature suggests cognitive skills required for safe driving may gradually diminish (Carr *et al.* 2005). A diagnosis of dementia alone is not sufficient evidence to recommend driving retirement, because the severity and impact of dementia may vary between individuals (Brown *et al.* 2005a, Perkinson *et al.* 2005). Some individuals living with a dementia continue to drive, despite evidence of compromised capacity (Adler & Kuskowski 2003). Others show reluctance to stop driving, particularly when the decision is imposed on them (Liddle *et al.* 2008). Those reluctant to accept negative driving assessment outcomes report that the assessment process is 'not fair' and does not accurately reflect actual capacity to drive (Perkinson *et al.* 2005, Byszewski *et al.* 2010).

A combination of psychometric tests are used in clinic-based assessments of cognitive capacity to drive. These

assessments are not dementia-specific and are considered to be of limited use by clinicians when assessing driving capacity among those with very mild or mild dementia (Fox *et al.* 1997, Molnar *et al.* 2006a). Current research claims that the most reliable method for assessing fitness to drive for individuals experiencing mild effects of dementia is an on-road driving assessment by a qualified assessor, with six-monthly reviews conducted from the time of diagnosis until driving ceases (Molnar *et al.* 2006b). Health practitioners, researchers and licensing authorities consider these on-road assessments provide objective information about fitness to drive (Fox *et al.* 1997, Perkinson *et al.* 2005, Austroads National Road Transport Commission 2012, Alzheimer's Australia 2010). However, a recent review by Martin *et al.* (2013) published in the Cochrane Database of Systematic Reviews concluded that there remains insufficient evidence that clinic-based, simulated or on-road assessments positively impact on outcomes for predicting driver safety for drivers with dementia.

For Australian medical practitioners there is no legal obligation to report a patient's diagnosis of dementia (Carmody *et al.* 2013). Mandatory reporting obligations for impaired physical or cognitive fitness to drive are only legislated in South Australia and the Northern Territory (Brown *et al.* 2005a, Australian and New Zealand Society for Geriatric Medicine 2009, Carmody *et al.* 2014). When a clinician assesses an individual as demonstrating symptoms of dementia that significantly affect daily living activities, determining fitness to drive is more straightforward. In contrast, when a person with dementia presents with only 'mild' effects on routine activities and cognitive function, fitness to drive should be determined on a case-by-case basis (Carmody *et al.* 2012). The importance of addressing fitness to drive for those with dementia has been defined in position statements published in Canada, USA, Australian and New Zealand (Lyketsos *et al.* 2006, Hogan *et al.* 2008). Hogan *et al.* (2008) outlined approaches to managing driving retirement in the Canadian Medical Association Journal including the family doctor's responsibility to monitor and counsel patients with progressive dementia who will eventually need to cease driving. Concurring with the Australian and New Zealand Society for Geriatric Medicine (2009) position statement, Hogan *et al.* also recommended that: (i) fitness to drive for drivers with mild dementia cannot be solely determined using a brief cognitive test; and (ii) clinicians should rely on an off-road and on-road assessment.

Research on driving and dementia has focused primarily on two topics: (i) identification of the most accurate method of assessing fitness to drive (Molnar *et al.* 2006b);

and (ii) development of educational awareness programmes about alternative lifestyle choices for older individuals when driving is no longer a safe option (Liddle *et al.* 2005). Evidence regarding the efficacy of educational awareness programmes for the driver with dementia is limited. Most studies involving driver perspectives on driving retirement decisions exclude the opinions of drivers with dementia (Alzheimer's Australia 2005, University of Michigan Transportation Research Institute 2006, Hartford Financial Group and MIT AgeLab 2007, Andrew *et al.* 2013). It is essential that strategies to enhance driver acceptance of driving cessation be informed by consumer opinion.

The review

Aim

The aim of this integrative review was to synthesize primary research exploring decision-making practices used to determine the time to retire from driving for individuals living with a dementia. Specific objectives were to identify: ways driving capacity is assessed when an individual has a dementia; strategies adopted by healthcare practitioners to provide driving related decisional support to individuals living with a dementia; and reasons why some individuals successfully retire from driving whilst others continue to drive despite awareness of cognitive impairment influencing other daily activities.

Design

An integrative literature review was undertaken to investigate the relationship between dementia and driving retirement decision-making practices. The integrative review framework, informed by Whittemore and Knafl (2005), was adopted because it enhances rigour when reviewing a combination of primary studies with diverse methodologies. In contrast to systematic reviews, primary studies that applied qualitative and mixed methods were also included (Kempainen *et al.* 2012).

Search methods

Search terms relating to assessment of driving and dementia were trialled and the following search terms developed: truncations of 'dementia OR Alzheimer' combined with 'drive' (truncated) and 'assess' (truncated), using the Boolean operator 'AND'. A three-phase search was then undertaken: (i) database search; (ii) incremental search and (iii) applying inclusion and exclusion criteria to focus the search (Figure 1).

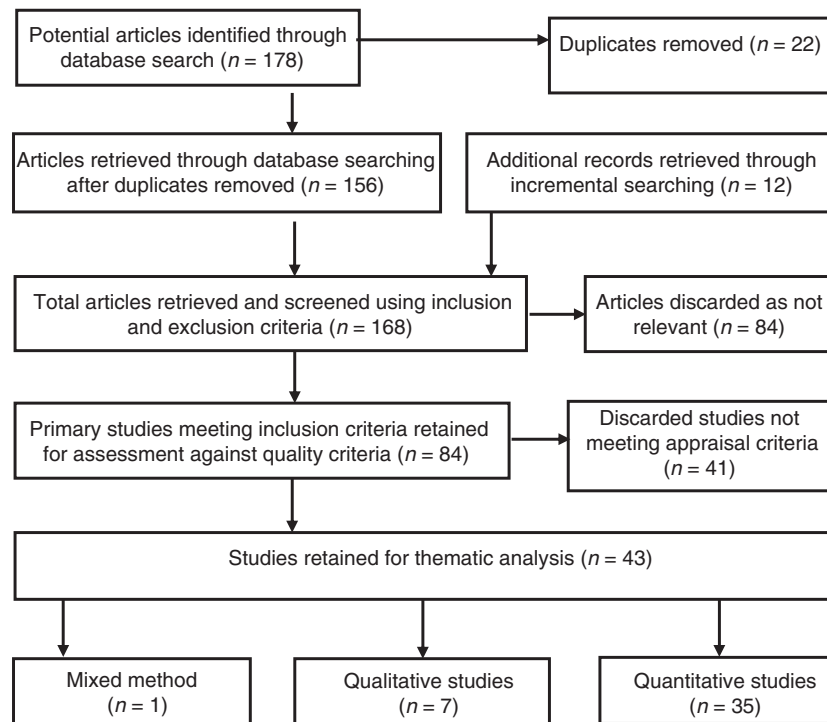


Figure 1 Flow Diagram of integrative review (adapted from PRISMA, 2009)

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Published between 1997–2012	Published prior to 1997
Published in English language	Published in language other than English
Primary research article	Article other than primary research
Contained key search words	Did not contain key search words
Related to loss of ability to drive safely and dementia	Related to loss of ability to drive that did not include those with dementia
Related to validity and reliability of tests of fitness to drive that assess drivers with dementia.	Related to validity and reliability of tests of fitness to drive that did not assess drivers with dementia.

- (i) Database search: Four electronic databases were searched: Medline; CINAHL; Web of Science; and Google Scholar for English language publications 1997–2012. Articles from 1997 were included because primary research published at this time continues to inform contemporary clinical practice and policy (Fox *et al.* 1997, Hunt *et al.* 1997)
- (ii) Incremental search: citations of articles retrieved from the database search were hand searched to minimize bias and maximize the number of relevant studies identified (Whittemore & Knafl 2005).

- (iii) Applying inclusion and exclusion criteria: retrieved articles were reviewed against the following: (a) inclusion of all types of primary research investigating the relationship between dementia and loss of capacity to drive safely; (b) exclusion of opinion-based and editorial publications; and (c) exclusion of studies investigating the validity and reliability of tests of fitness to drive that did not assess drivers with dementia (Table 1).

Search outcome

The database search identified 156 articles and an additional 12 primary articles were retrieved by hand searching. A total of 168 articles were critiqued against the inclusion and exclusion criteria to focus the search, and 84 articles were discarded (Table S1 online). The remaining articles ($n = 84$) were retained for further assessment against the quality appraisal criteria.

Quality appraisal

The first author critically appraised the retained articles using methodological assessment tools from the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit 2009). The second author then reviewed appraisal outcomes to ensure consensus.

Quantitative and mixed method studies were ranked using the National Health and Medical Research Council (2009) Evidence Hierarchy and were then scored against a 'body of evidence matrix' (CASP 2009). A four-point scale (Excellent-A; Good-B; Satisfactory-C; and Poor-4) (National Health and Medical Research Council 2009) was applied and those studies scoring satisfactory (C) and above were retained for data abstraction and synthesis.

Qualitative studies were reviewed using the CASP appraisal tool: '10 questions to help make sense of qualitative research' (National Health and Medical Research Council 2009); and ranked according to qualitative design (low/medium/high). Those studies ranked as medium and above were retained for data abstraction and synthesis. A total of 43 studies that met the quality appraisal criteria were retained: qualitative ($n = 7$); mixed method ($n = 1$); quantitative ($n = 35$) studies (Table S2 online).

Data abstraction

Thematic analysis was applied to the 43 retained articles using inductive coding to compare and contrast findings related to exploring driving retirement decision-making practices for drivers living with a dementia (Corban & Strauss 2008). Commonalities identified across articles were recorded and categorized to capture important recurring concepts.

Synthesis

Using QSR Nvivo 9 (2009) to manage data, common findings were analysed to establish patterns of meaning and identify emergent themes. A themes matrix was constructed to ensure all major themes related to the aim of the integrative review were identified (Hibbert 2004, Hart 2005).

Results

The articles retained for data abstraction and synthesis generated six themes exploring driving decision-making practices for individuals living with a dementia:

- (i) dementia may compromise the complex task of driving ($n = 6$);
- (ii) defining onset and severity of dementia is problematic ($n = 7$);
- (iii) symptom progression impacts on driving skills ($n = 6$);
- (iv) assessment of fitness to drive remains subjective ($n = 12$);
- (v) some drivers are reluctant to accept negative assessment outcomes ($n = 12$); and

- (vi) the search for effective strategies to enhance acceptance of driver retirement continues ($n = 17$).

While no individual articles were represented across all six themes, several articles were represented across more than one theme (Table 2).

Dementia may compromise the complex task of driving

This theme was informed by six quantitative studies that explored the complexity of driving with regard to the impact of dementia on capacity to drive. An early prospective study by Hunt *et al.* (1997) evaluated the on-road driving performance of drivers with dementia ($n = 55$) and age-matched controls ($n = 58$). The authors found significant association between driving performance and dementia status ($P = 0.001$, CI not reported). In contrast, a survey by Carr *et al.* (2000) compared crash rates between those older drivers with dementia ($n = 63$) and older drivers without dementia ($n = 58$), claiming no significant difference in crash rates when adjusted for distances driven, although those with dementia had more at-fault crashes. Limitations to this study included only reporting statistical significance between drivers with and without dementia for miles driven ($P = 0.02$, CI not reported).

Findings from a cross sectional study of cognitively impaired drivers ($n = 178$) and drivers without cognitive impairment ($n = 202$) conducted by Valcour *et al.* (2002) suggested that drivers with lower cognitive assessment scores were less likely to be driving, however, statistical significance was not reported. This finding concurs with a survey by Adler and Kuskowski (2003) of male drivers ($n = 53$) and their informants regarding driving history, habits and expectations. Lower MMSE was a significant predictor of driving cessation ($P = 0.02$, 95% CI CI, 0.68-0.97).

Safety implications for those with symptoms of memory loss and inability to recognize familiar places have been investigated in a retrospective review of media reports by Hunt *et al.* (2010) of drivers with dementia becoming lost ($n = 207$). Drivers who became lost, or died, were travelling to or from familiar places, illustrating the potential for dementia to compromise the high-level cognitive skills required to negotiate dynamic traffic situations.

Defining onset and severity of dementia is problematic

This theme was informed by one qualitative study and six quantitative studies. Challenges related to the natural progression of dementia and the subsequent impact on fitness to drive emerged.

Table 2 Themes identified from synthesis

Themes identified	Primary studies informing each theme	
Dementia may compromise the complex task of driving	1 Adler and Kuskowski (2003) 2 Carr <i>et al.</i> (2000) 3 Hunt <i>et al.</i> (1997)	4 Hunt <i>et al.</i> (2010) 5 Kay <i>et al.</i> (2009c) 6 Valcour <i>et al.</i> (2002)
Defining onset and severity of dementia is problematic	1 Adler and Kuskowski (2003) 2 Brown <i>et al.</i> (2005a) 3 Cottrell and Wild (1999) 4 Ducheck <i>et al.</i> (2003)	5 Fox <i>et al.</i> (1997) 6 Perkinson <i>et al.</i> (2005) 7 Valcour <i>et al.</i> (2002)
Symptom progression impacts on driving skills	1 Adler (2010) 2 Carr <i>et al.</i> (2005) 3 Ducheck <i>et al.</i> (2003)	4 De Simone <i>et al.</i> (2007) 5 Uc <i>et al.</i> (2004) 6 Whelihan <i>et al.</i> (2005)
Assessment of fitness to drive remains subjective	1 Berndt <i>et al.</i> (2008) 2 Brown <i>et al.</i> (2005b) 3 Brown <i>et al.</i> (2005a) 4 Dobbs (1997) 5 Ducheck <i>et al.</i> (2003) 6 Fox <i>et al.</i> (1997)	7 Hunt <i>et al.</i> (1997) 8 Kay <i>et al.</i> 2008 9 Kay <i>et al.</i> (2009a) 10 Kay <i>et al.</i> (2009b) 11 Lincoln <i>et al.</i> (2010) 12 Lovell and Russell (2005)
Some drivers are reluctant to accept negative assessment outcomes	1 Adler <i>et al.</i> (2006) 2 Adler (2010) 3 Byszewski <i>et al.</i> (2010) 4 Freund <i>et al.</i> (2005) 5 Freund and Szinovacz (2002) 6 Jett <i>et al.</i> (2005)	7 Kostyniuk and Molnar (2008) 8 Liddle <i>et al.</i> (2005) 9 Lincoln <i>et al.</i> (2006) 10 Perkinson <i>et al.</i> (2005) 11 Rudman <i>et al.</i> (2006) 12 Taylor and Tripodes (2001)
The search for effective strategies to enhance acceptance of driver retirement continues	1 Adler <i>et al.</i> (2006) 2 Adler (2010) 3 Baldock <i>et al.</i> (2006) 4 Brown <i>et al.</i> (2005a) 5 Brown <i>et al.</i> (2005b) 6 Byszewski <i>et al.</i> (2010) 7 Cottrell and Wild (1999) 8 Dobbs <i>et al.</i> (2009) 9 Kay <i>et al.</i> (2009c)	10 Jett <i>et al.</i> (2005) 11 Liddle <i>et al.</i> (2005) 12 Mizuno <i>et al.</i> (2008) 13 Perkinson <i>et al.</i> (2005) 14 Shope and Eby (1998) 15 Snellgrove and Hecker (2002) 16 Stern <i>et al.</i> (2008) 17 Wild and Cottrell (2003)

Onset of initial symptoms and clinical diagnosis do not occur simultaneously. For example, an Australian study by Fox *et al.* (1997) undertaken of drivers with probable Alzheimer's disease ($n = 19$) concluded that the duration of symptoms was not a predictor of driving assessment outcomes ($P = 0.477$, CI not reported). Decline in driving performance over time for drivers with early-stage dementia was found in a longitudinal study by Ducheck *et al.* (2003). There was a significant difference between drivers with dementia ($n = 50$) and healthy controls ($n = 58$) in length of time taken to be deemed no longer fit to drive ($P = 0.006$, 95% CI 102–109).

While driving will eventually cease due to diagnosis (Valcour *et al.* 2002), the continuum between onset of symptoms and eventual inability to drive safely is difficult to define (Fox *et al.* 1997, Brown *et al.* 2005a,b, Perkinson

et al. 2005). A study of drivers with very mild ($n = 33$) and mild dementia ($n = 17$) by Brown *et al.* (2005a) found that 94% of participants with Alzheimer's disease self-rated their driving as safe. In contrast, the driving instructors conducting the on-road assessments rated 46% of those with very mild dementia and 41% with mild dementia as safe to drive. Adler and Kuskowski (2003) investigated driving cessation among male drivers with dementia (53) and concluded that driving continued long after onset of symptoms. Cessation was usually abrupt and unplanned, requiring intervention from family carers and physicians. Duration of disease was not associated with on-road assessment outcomes ($P = 0.477$).

Clinical assessments used to determine fitness to drive for individuals with cognitive impairment do not accurately predict driver safety for drivers with very mild and mild

dementia (Duchek *et al.* 2003). Reliance on these assessments to screen for driving safety can lead to premature licence cancellation for some drivers with dementia, whilst failing to identify those who are unsafe (Fox *et al.* 1997). Perkinson *et al.* (2005) conducted focus groups with stakeholders including advocates, drivers with dementia, health professionals and law enforcement professionals. Key beliefs identified using thematic analysis provided insight into the difficulties associated with defining the time of onset and natural progression of symptoms. A longitudinal study by Cotrell and Wild (1999) conducted with 35 individuals living with a dementia and their carers, including current drivers ($n = 19$) and retired drivers ($n = 16$), found that drivers did restrict areas of their driving voluntarily. However, discrepancy between carer and driver ratings of awareness of driving deficits in relation to MMSE scores was also found ($P < 0.007$). The authors suggested an awareness deficit may be associated with a driver's failure to restrict their driving, in particular awareness for attention. Therefore, when the severity of symptoms leads practitioners and family carers to raise concerns about driver safety, the capacity of the person with dementia to participate in decision-making and understand the reasoning behind unfavourable assessment findings may be compromised.

Symptom progression impacts on driving skills

This theme was informed by one qualitative study and five quantitative studies.

Drivers diagnosed with dementia will need to consider retirement from driving as their illness progresses. A study by Uc *et al.* (2004) of 32 drivers with dementia and 136 controls assessed navigation and safety errors during a route-following task. While drivers with mild dementia demonstrated normal basic vehicle control abilities, significant differences were found between drivers with dementia and controls for (i) incorrect turns ($P < 0.001$, 95% CI 1.16–1.40); (ii) becoming lost ($P < 0.0159$, 95% CI 1.06–1.59); and (iii) making at-fault safety errors ($P < 0.0001$, 95% CI 1.12–3.85).

The relationship between driving competence, cognitive deficits and driving behaviour has been identified in studies by De Simone *et al.* (2007) and Whelihan *et al.* (2005). Investigation by De Simone *et al.* (2007) hypothesized that personality and social cognition deficits in fronto-temporal dementia (FTD) would have an impact on driving abilities. The authors found a significant correlation between severity of FTD and simulated driving tasks ($r = 0.53$; $P < 0.05$). Similarly, results of the randomized control trial by Whelihan

et al. (2005) comparing 23 drivers with dementia and 23 controls found significant differences in cognitive test scores between the intervention and control groups ($P < 0.001$, CI not reported).

Assessment of fitness to drive remains subjective

A total of 12 quantitative studies informed the theme, assessment of fitness to drive remains subjective. There were no randomized control studies conducted to investigate clinic-based, on-road or other assessments of safe driving capacity for drivers with dementia. Insufficient level I and level II evidence available in the research (National Health and Medical Research Council 2009) to inform current driver assessment practices may justify concerns raised by some drivers and family carers about the reliability and validity of driving assessments.

Contemporary evidence-based practice advocating assessment of fitness to drive for those with dementia is informed by the premise that: (i) there are no definitive clinic-based assessments that can accurately predict fitness to drive for those diagnosed with very mild to mild dementia; and (ii) on-road driving assessments are currently considered more accurate than clinical assessments (Dobbs 1997, Fox *et al.* 1997, Hunt *et al.* 1997, Duchek *et al.* 2003). However, drivers and their carers raise concerns about the validity and reliability of on-road assessments, given the subjective methods of delivery and evaluation. For example, a longitudinal study by Hunt *et al.* (1997) analysed inter-rater reliability of a standardized on-road assessment route designed for drivers with dementia. The authors tested a convenience sample of 58 age-matched controls with 36 drivers with very mild dementia and 29 drivers with mild dementia. Results indicated a significant association between driving performance and dementia status ($P < 0.001$, CI not reported) and inter-rater reliability ranged from $k = 0.85$ – 0.96 . However, not all on-road assessments are conducted using a standardized route and the outcome relies on assessor observation over a limited timeframe in a testing environment (Brown *et al.* 2005a).

For individuals with very mild to mild dementia, use of cognitive screening tools have been considered poor predictors of fitness to drive while an on-road assessment has greater accuracy and is referred to as 'the gold standard' (Fox *et al.* 1997, Brown *et al.* 2005b, Lovell & Russell 2005, Berndt *et al.* 2008, Dobbs *et al.* 2009). However, quantitative research by Kay *et al.* (2009b) and Lincoln *et al.* (2010) found higher than previously obtained correlation between accuracy of clinic-based test scores and on-road assessments. The prospective study by Kay *et al.*

(2009b) of 91 drivers with varying cognitive and/or physical diagnoses aged 16–86 years, compared the psychometric ratings of the DriveAware questionnaire (clinic-based assessment) with on-road driver safety ratings. The authors found good evidence for construct validity and inter-rater reliability of the clinic-based assessment, i.e. lower cut off score 95% CI –11% to 13%; upper level cut off score 95% CI –17% to 14% and recommended further investigation to validate findings. Lincoln *et al.* (2010) found a clinical test battery (inclusive of: MMSE, SDS, SORT, stroop colour vision, D-KEF trail making, VOSP, BADS, MAIPB) and a standardized on-road assessment (Nottingham Neurological driving assessment) predicted safety to drive in 76% of drivers (sensitivity 80%, specificity 61.5%). The authors concluded that the test battery is useful for identifying those who would benefit from on-road assessment; however, reliance on clinical results as an alternative to an on-road assessment was not a recommendation.

Some drivers are reluctant to accept negative assessment outcomes

Twelve studies, including one mixed method; five qualitative; and six quantitative studies informed this theme. While on-road assessments are considered more accurate for predicting driving safety compared with clinical tests (Lincoln *et al.* 2006) these assessments rely on observation of driving skills over a short period in an unfamiliar car and/or along unfamiliar driving routes (Brown *et al.* 2005a). Jett *et al.* (2005) interviewed health professionals ($n = 63$), older drivers ($n = 20$) and family members ($n = 91$) to identify effective and ineffective strategies for bringing about driving cessation. The authors concluded that driving cessation can occur voluntarily; however, for those not wanting to cease driving, the decision should be imposed. Byszewski *et al.* (2010) explored the perspectives of individuals living with a dementia who had been told to stop driving ($n = 15$) and their family carers ($n = 15$). Two themes were identified: (i) acceptance/resignation; and (ii) disagreement/rejection. Practical strategies to enhance acceptance of driving cessation included: addressing the issue of driving concern early; and providing greater detail about assessments used to determine fitness to drive.

Perkinson *et al.* (2005) sought opinion from a cohort ($n = 68$) of consumers, family carers and practitioners regarding reasons why some drivers with dementia resist driving retirement. Drivers with dementia ($n = 9$) believed their cognitive impairment did not affect their driving safety. Approximately half of the former drivers with

dementia ($n = 5$) believed they should have been allowed to continue driving. These findings concurred with results from the study by Byszewski *et al.* (2010) when 40% of drivers with dementia ($n = 15$) who had been advised by practitioners to cease driving accepted the recommendation ($n = 6$); 20% did not agree but resigned themselves to the decision ($n = 3$); and 40% rejected the recommendation ($n = 6$), insisting they remained fit to drive. Neither study reported reasons for the variation in participants' level of acceptance.

Several studies identified significant lifestyle and psychosocial implications accompanying licence cancellation, attributing reluctance to accept negative assessment outcomes to an adaptive grief response to diagnosis; loss of insight due to disease progression; or a combination of both (Freund *et al.* 2005, Jett *et al.* 2005, Adler *et al.* 2006, Liddle *et al.* 2008). For example, interviews conducted by Liddle *et al.* (2008) with nine retired drivers, three family members and six practitioners identified issues of awareness and acceptance of driving retirement. These findings confirm the need to implement acceptable driving retirement interventions (Taylor & Tripodes 2001, Freund & Szinovacz 2002, Freund *et al.* 2005, Rudman *et al.* 2006, Kostyniuk & Molnar 2008, Adler 2010, Byszewski *et al.* 2010).

The search for effective strategies to enhance acceptance of driver retirement continues

A total of 17 articles including one mixed method, five qualitative and 11 quantitative studies informed this theme. While tests for predicting fitness to drive in the decisional phase and lifestyle management for coping in the 'post-decision' phase are reported in primary studies, the merit of including drivers with dementia in the decisional phase does not appear to be sufficiently investigated (Dobbs *et al.* 2009). For example, a mixed method study by Liddle *et al.* (2005) explored the transport and lifestyle issues of people aged 65 years and over ($n = 234$) including current drivers ($n = 137$); retired drivers ($n = 56$); and non-drivers ($n = 41$). This study purposely excluded individuals with dementia. The authors compared current and retired drivers, finding lower life satisfaction ($P = 0.01$) and fewer present life roles ($P < 0.0001$) reported by retired drivers.

Adler (2010) addressed decisional conflict faced by drivers with dementia in a qualitative study of current drivers with dementia ($n = 20$), their spouses ($n = 20$) and spouses of former drivers with dementia ($n = 25$). When asked how people with dementia would know it was time to retire from driving respondents reported several 'flags' to indicate the time to cease driving was imminent. The need for a

shared approach that included the driver with dementia in monitoring fitness to drive safely was advocated and respondents recommended further investigation of ways this could be achieved. In a qualitative study by Mizuno *et al.* (2008), 79 family carers of individuals living with a dementia were surveyed to investigate: (i) major decision makers responsible for driving cessation of older adults with dementia; (ii) current practices used by family carers to facilitate driving cessation; and (iii) the necessary requirements for enabling the cessation of driving. It was found that 47% of carers believed individuals should make the decision to retire whilst 27% actually made the decision. Of those family members who doubted the ability of the individuals living with a dementia to drive (23%) only half attempted to encourage cessation. Carers reported several factors such as having another family member available to drive (84%) and encouragement from physicians (42%) facilitated cessation.

Primary studies investigating the value of educational awareness programmes to inform decisions about driving cessation with older drivers have generated positive results. It is important to note, however, that participant samples purposely excluded drivers with impaired cognitive function. For example, findings by Baldock *et al.* (2006) investigated self-regulation habits and attitudes in a community-based study in South Australia with drivers aged 60–92 years without dementia. The authors concluded that provision of educational resources, self-assessment strategies and opportunity to obtain passenger feedback would assist drivers to make decisions about their driving ability. A randomized control trial by Marottoli *et al.* (2007) also found that the provision of an education programme enhanced on-road performance for older drivers.

The efficacy of educational programmes to inform drivers with dementia about the potential impact on capacity to drive safely is supported by several studies. An early qualitative study by Cottrell and Wild (1999) found that when drivers with dementia ($n = 35$) became aware of a 'deficit' they were able to modify driving patterns and safely prolong their driving status. A qualitative study of practitioners and family carers of individuals living with a dementia ($n = 261$) by Jett *et al.* (2005) advocated an 'involved' strategy of intervention, inclusive of the driver who is facing decisions about driving retirement. Findings concur with a qualitative study by Byszewski *et al.* (2010) that sought opinion from drivers with dementia ($n = 15$) who were told to stop driving and their family carers. Findings suggested that timely access to information about dementia's progressive impact on driving safety could enable people with dementia to participate in

driving retirement decisions rather than face sudden, externally imposed recommendations to cease driving.

Findings from early research by Shope and Eby (1998) and Wild and Cottrell (2003) concur with contemporary opinion-based literature. Healthy older drivers are able to self-regulate their driving behaviours and make adjustments to increase their safety; whilst older drivers with impaired cognitive functioning failed to recognize the potential impact of their deficits and do not modify their driving habits to accommodate them (Pachana & Petrowski 2006). A pilot study by Wild and Cottrell (2003) of drivers with mild dementia ($n = 15$) and age-matched healthy controls ($n = 15$) found drivers with dementia self-rated their driving ability as higher compared with controls whilst actual driving performance was significantly worse.

Discussion

The outcome of this integrative review is the acknowledgment that driving is a complex task, demanding cognitive and physical skills that may be compromised during the natural process of ageing or through onset of 'other' dementias. While the loss of licence may represent a loss of independence for the driver with dementia, a balance is required to address individual rights and safety for all road users. This will remain a social concern and a broadly debated community issue into the future. For those individuals living with a dementia, the most appropriate time to retire from driving needs to be assessed on a case-by-case basis. While the on-road assessment is considered the most accurate predictor of capacity to drive for those with mild to very mild dementia, the fact is that some drivers are reluctant to accept evidence that their driving skills are impaired and that their safety and others' safety could be compromised. This highlights the importance of research into the efficacy of decisional support tools for drivers with a recognized dementia who face potential decisional conflict about driving retirement.

This integrative review included quantitative, qualitative; and mixed method studies. Qualitative studies were included because generating an understanding of the importance of driving to individuals living with a dementia is required in this field of research (Goldsmith *et al.* 2007). A rigorous approach was adopted by the lead author to critically appraise the quality of the articles retrieved to determine those to be retained for data abstraction and synthesis, however, limitations were identified. While consensus was reached with authors regarding those articles to retain and discard, rigour would have been further enhanced by enlisting more than one member of the research team at the commencement of the critical appraisal process.

Conclusion

Findings from this integrative literature review identified a large body of knowledge exploring the issues of driving cessation for drivers living with a dementia. However, a challenge remains for practitioners, drivers and their family carers regarding how best to address this highly emotive issue. While practitioners acknowledge difficulty initiating conversations with patients, the family carers would welcome early conversations with medical ‘experts’. Nurses and other health practitioners need to be aware of enablers and barriers to acceptance of driving retirement when providing interventions to support people living with a dementia and their family carers. The themes generated from this review could provide a structured approach to address this sensitive topic in a timely manner. Further research is recommended to determine the decisional support needs of drivers who recognize they have a dementia. Validation as to the effectiveness of a decisional support tool to facilitate acceptance that capacity to drive safely may become compromised is required.

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Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

Supporting Information

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